



## President Report Fiscal Year 2008

Greetings to all Members and Friends of F.I.R.S.T.:

When preparing comments for the President's Annual Report message for the Foundation's spring newsletter, I do something dangerous: look back to review my comments from previous years to remember where we were, what we thought was important and relevant at the time, and measure how we are doing together on our journey as a group of dedicated and supportive members.

In the 2007 newsletter, I spoke of our *Soaring to New Heights*, a theme that was used for a very successful 2006 Family Conference in Atlanta, Georgia.

The following year, I described how the Board of Directors better defined our organizational mission: to Educate, Inspire, and Connect those touched by ichthyosis and related disorders; and set in motion multiple, specific strategic initiatives intended to sustain the "soaring momentum" of F.I.R.S.T.

Having a strategic plan is important to all successful organizations, for without one an organization is rudderless. A good strategic plan sets in motion a consistent, shared vision that along with the necessary commitment to its execution allows an organization to "steer" how it will "soar." You want the plan to provide focus and you want it to be simple and easy to measure yourself against its aims. And when special challenges arise, our collective belief and motivation as a board was that a good strategic plan for F.I.R.S.T. would define what is most important to our members and what must get done to advance our mission!

Clarity of purpose has never been greater, and a focus on what matters never more required. In spite of the unprecedented challenges of a broad economic downturn, F.I.R.S.T. remains committed to operating at peak efficiency through our exceptional staff in Philadelphia. Moreover, we are successfully implementing eight (8) key initiatives by 2011 that represent real opportunities to grow our organization to the benefit of all its members, friends and benefactors.

Not all of the projects have a *wow factor* to them. For example, the continued growth of F.I.R.S.T. has created a need for our relatively small staff to cost-effectively serve more people, and thus we needed to improve our infrastructural capacity. Characterized somewhat like air and water for our organization, the following two strategic projects represent vital contact tools that will be utilized for improved communication with, service to, and programming for our members well into the future.

- New Database Management System – after significant research and diligence being done on multiple vendor software products, management decided on a system with full training and implementation to occur by 2009. This new software will enable us to maintain better connection with our members and donors, and communicate frequently on many levels with more of a personalized touch than possible in the past.

- Website Re-design – Accurate Imaging has been selected as the vendor to update and re-build our website, a process that will continue through most of 2009. Clearly, the website is the major portal of entry to F.I.R.S.T. and used to obtain electronic copies of accurate information about the ichthyoses. As such, it is essential that our website be designed so it is more manageable by our internal staff to keep content and news announcements “current” and “up-to-date,” its overall utility be upgraded to meet current standards, and that our website be found easily navigable by all that visit it.

Throughout 2009, you will see signs of these fundamental improvements as they become fully implemented.

There are certainly strategic projects that do have *wow factors* to them and have potential outcomes that the board believes are game-changers for current and future members of F.I.R.S.T. Four of these projects aim to:

- Continue our focus on grass-roots fundraising projects by providing training and support and to diversify our fundraising efforts to raise a dedicated \$3 million endowment to fund new and ongoing research. We are actively recruiting a development director to lead this activity.
- Aggressively market foundation activities to educate and reach more prospective members, clinicians and donors about our programs, services and benefits of membership – we have completed the development of our first major piece, i.e. a 12-minute video production from our very successful 2008 National Family Conference in Chicago, and will utilize the complete or targeted versions at multiple venue throughout the upcoming years.
- Strengthen our regional support network by developing eight (8) specific geographic regions that interact and communicate regularly and meet “locally” during the off-year of the National Family Conference - locations have already been determined for four regional meetings, coordinators and volunteers are being recruited, and the date has been determined for the Region 1 conference.
- Launch a HIPAA-compliant telemedicine program that would be one of the first in the world to connect members and families in need, and their clinical support, to a team of dermatology experts recruited by F.I.R.S.T. to review their case history and communicate to the attending physician – select members of our Medical and Scientific Advisory Board are spear-heading this activity and once our partnership with the University of Missouri to host the technology infrastructure is completed, our organization is well along the path to accomplishing this goal of connecting members needs with expert medical consultation.

*Just imagine for a moment.....*

Imagine an organization that is retaining and growing its membership, physician, friends and donor base every year by double digits, has operational access to the most efficient tools for communicating on a timely and regular basis, produces the highest quality medical and vendor informational pieces to emphasize its mission and capability to positively impact people’s lives, drives a thriving network

of interaction across the world through its website portal, educational literature, physician resource network, telemedicine initiative, regional support networks and bi-ennial national family conferences, provides funds for research that are directed by a world class scientific review committee and applied to disease areas that matter most to our members, and is managed by a highly energized staff of professionals under the extraordinary leadership of an executive director like Jean Pickford!

*Now that's a WOW - Welcome to F.I.R.S.T.!*

The overall health of any organization is often judged by whether first, it has the financial resources to carry out its mission, and second, does it have the full and active engagement of its members. As you can tell from our CFO Report, the financial assets of F.I.R.S.T. have grown steadily in recent years, both in non-restricted and restricted funds. Plain and simple, this has been due to the hard work of our members as they are involved each and every month in critical and various grass-roots fundraising projects, through the generosity of several large donors that have committed funds for focused activities during the past several years, and the grant writing of our internal staff. Working together, F.I.R.S.T. has experienced a steady expansion of its operating potential and reserves for key initiatives.

Full and active engagement of our members, and the depth of their emotional commitment to F.I.R.S.T., can be measured in so many ways. Every issue of our newsletter, the letter from our Executive Director and every article and note conveys substantial engagement at multiple levels of our membership. However, the most evident for me is your attendance at the national family conference every two years. That is where you will find all of the physical and emotional assets of the organization on full display for everyone to tap into and gain benefit. Chicago was the best attended conference yet, with a record-breaking 400 individuals present. Now that's a sign of engagement! We look forward to the June 2010 Family Conference in Orlando with great anticipation to see old friends, make new acquaintances and see the "focus" on children's faces when they spot Mickey for the first time.

In closing, I wish to thank all members for your dedication to F.I.R.S.T., your continued generous donation of time and resources to helping us achieve our unique mission and strategic objectives, and trust that you and your family will continue to find our organization as the best resource available to provide emotional support, information, advocacy and research funding for better treatments and an eventual cure for those affected with Ichthyosis or a related skin disorder. Together, we continue to make a big difference and a very positive impact!

Most sincerely,

David R. Scholl, Ph.D.  
President